ÉQUIPE SANTÉ ONTARIO
Ottawa
ONTARIO HEALTH TEAM

Socio-Demographic Data Strategy Implementation Resource Toolkit

First Edition:
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Overview: The Socio-Demographic Data Common List & Purpose of this Toolkit

Through consultation with members of the Ottawa Health Team – Équipe Santé Ottawa (OHT-ÉSO) Performance Measurement Working Group comprised of staff from Centretown Community Health Centre, Ottawa Public Health, and The Ottawa Hospital, common definitions have been selected for a series of socio-demographic indicators, sourced from validated survey tools produced by the Measuring Health Equity project, the Canadian Institute of Health Information, and Statistics Canada, among others.

The ***OHT-ÉSO Socio-demographic Data Common List*** has been compiled to support local health care partners to align how client and patient socio-demographic data is recorded and provides a recommended best practice guide towards how to collect this data rather than a set of mandatory standards. This guide provides additional detail on each indicator that can help organizations understand which data points they might prioritize for collection, and the rationale and benefits for collecting each type of socio-graphic data. An accompanying document, the ***OHT-ÉSO Socio-Demographic Data Collection Rationale & User Guide*** provides additional detail on each indicator, including rationale and use case scenarios that can support decisions about what data could be collected for specific care settings.

To support implementation of socio-demographic data collection and use, the ***OHT-ÉSO Socio-demographic Data Strategy Implementation Resource Toolkit*** has been developed to provide partner organizations and providers an implementation roadmap, complete with examples and tools, to help health care providers and organizations to implement these processes.

How To Use This Toolkit

This implementation resource guide is structured based on, and closely adapted from a Resource Guide for Public Health Units from the *"Lessons Learned from the Collection of Sociodemographic Data during the COVID-19 Pandemic"* Locally Driven Collaborative Project (LDCP) which was led by Peel Region Public Health, Ottawa Public Health, , the Upstream Lab, with financial support from Public Health Ontario. The LDCP project was designed to document Ontario public health unit lessons learned collecting sociodemographic data during the COVID-19 pandemic, and to build support for public health units to start or expand collection of socio-demographic data. In many cases, language, recommendations and sequential steps are taken directly from the LDCP project deliverables.

The sections below follow a general sequential order to support the implementation of a socio-demographic data collection and use strategy, however the implementation process is not a strictly linear process. Organizations may find it useful to start at different steps, and use the materials and resources included below in whatever order or manner best suites their current state, needs, and capacities for implementing new or strengthening existing socio-demographic data collection strategies. Some stages will likely require more time and resources than others.

Many of the resources listed in this document have also been included in an appendix at the end of the toolkit, arranged by area of functional support for quick access.

Confirm and demonstrate organizational commitment to socio-demographic data (SDD) collection through senior leadership championing.

Items to Consider:

- How this work aligns with, and supports your organization's commitment to health equity principles. OHT-ÉSO partner organizations have signed the OHT-ÉSO Health Equity Charter, which is closely aligned with this work and included in this section's resources.
- Establishing SDD collection and use as an organizational priority to support equity measurement and quality improvement.
- Including SDD activities in organizational Annual Service Plans and Budgets, strategic plans, operational plans, etc.; ensure adequate, dedicated resources for SDD collection, analysis and use.
- Developing organizational policies and procedures for SDD collection, storage, analysis, and use.
- Communicating clear goals and objectives for the collection of SDD; namely, to better understand who is accessing programs/services, to modify programs/services to address the unique needs of clients/populations, and to collaborate with and engage communities to advance health equity.

Resources

Data Collection Readiness Checklist | Measuring Health Equity Project.

Guide to Demographic Data Collection in Health Care Settings | Ontario Health, Sinai Health, UHN.

OHT-ÉSO Health Equity Charter

Presentation: Using Data to Advance Health Equity | Alliance for Healthier Communities.

SDD Collection Implementation Training Materials | Measuring Health Equity Project.

Review existing resources and evidence for SDD collection.

Items to Consider:

- Lessons learned and evidence for SDD collection and use from healthcare settings (e.g., We Ask Because We Care, Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres).
- Guidance for engaging equity-deserving groups (e.g., National Collaborating Centre for Determinants of Health) and data governance considerations for SDD collection and use (e.g., First Nations Principles of Ownership, Control, Access, and Possession – OCAP® and the Black Health Equity Work Group's Engagement, Governance, Access, and Protection framework - EGAP).

Resources

OHT-ÉSO SDD Collection Rationale & User Guide

Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres | Measuring Health Equity Project.

Lessons Learned from the Collection of Sociodemographic Data during the COVID-19 Pandemic | Public Health Ontario, based on research by Ottawa Public Health, Region of Peel and Upstream Lab.

- Final Report and Recommendations
- Resource Guide for Implementing & Scaling SDD Collection
- Webinar Recording

Socio-demographic Data Implementation Guide | Alliance for Healthier Communities

Resource Package to Support Socio-demographic Data Collection & Use | Alliance for Healthier Communities.

Resources for Engaging Equity-Deserving Groups

The First Nations Principles of OCAP | First Nations Information Governance Centre

Indigenous Data Privacy Framework | Indigenous Primary Health Care Council.

Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities in Ontario | Black Health Equity Working Group.

Considerations for collecting data on race and Indigenous identity during health card renewal across Canadian jurisdictions | Pinto et. al., Canadian Medical Association Journal.

Determine what specific programs/services would benefit from SDD collection.

Items to Consider:

- SDD collection at an individual level is one tool, but not the only tool, for assessing and monitoring health inequities. Understanding how the data will/could be used is one way to determine if SDD is the right tool.

- What are the key questions driving SDD collection? Is SDD needed to answer the key questions?

- What does currently available evidence/data say about populations most affected by the health issue or program/service – locally, provincially, nationally?

- Starting within a select program area (or areas) supports capacity building and continuous quality improvement as SDD collection practices evolve and expand to other areas.

Resources

Alliance Member Case Studies on Sociodemographic Data Collection and Use | Alliance for Healthier Communities.

Poverty: A Clinical Tool for Primary Care Providers | Centre for Effective Practice.

Gender-based Analysis Plus (GBA Plus) | Women and Gender Equality Canada

A Brief Tool to Screen Patients for Precarious Employment: A Validation Study | Upstream Lab SPARK Study.

Building a Foundation to Reduce Health Inequities: Routine Collection of Sociodemographic Data in Primary Care | Upstream Lab SPARK Study.

Routine Collection of Sexual Orientation and Gender Identity Data: A Mixed-Methods Study | Upstream Lab SPARK Study.

Routine Identification of Patients with Disabilities in Primary Care: A Mixed-Methods Study | Upstream Lab SPARK Study.

Engage early and ongoing with key community partners (e.g., community leaders, advocacy groups, and members of equity-deserving groups represented in the data) to discuss the rationale for SDD collection and use to learn about the SDD constructs that matter most to their communities.

Items to Consider:

- Relying upon existing relationships with communities, particularly unique equity-deserving groups.
- Reviewing best practice approaches for engaging equity-deserving groups.
- Understanding how the community partners would like to see ongoing engagement from collection through to dissemination and use.
- Seeking to understand community information needs, preferences and concerns about the collection and use of SDD.
- Identifying opportunities to build trust and communicate about the importance of SDD collection and use for equity measurement and quality improvement.
- Engaging with key community partners to discuss and interpret preliminary analysis findings.
- Fulfilling commitments to key community partners by sharing findings from data analyses in the appropriate format and location. This may or may not include public reporting.

Resources

IAP2 Spectrum for Community Engagement | Tamarack Institute.

Community Engagement Planning Canvas Tool | Tamarack Institute.

Index of Engagement Techniques | Tamarack Institute.

Engaging Communities in your Data Collection Initiative| Health Commons Solutions Lab.

Let’s Talk: Community engagement for health equity | National Collaborating Centre for Determinants of Health

Engage early with internal staff/teams to build capacity and comfort to collect this information from clients as part of service delivery practice.

Items to Consider:

- Change management strategies such as internal SDD champions to drive the work forward and build team buy-in.

- Developing staff/team engagement surveys to assess knowledge of the importance of SDD and level of comfort collecting this information from clients.

- The potential role, based on community feedback, of community partners in championing and supporting SDD collection with staff.

- Documenting and sharing examples of how SDD has been analyzed and used for program decision-making.

Resources

Introduction to Health Equity Online Course | National Collaborating Centre for Determinants of Health.

Training Video: Collecting Racial/Ethnic/Indigenous Identifiers during COVID-19 | Shared Health Manitoba.

List: Webinars on Racism, Anti-racism and Racial Equity | National Collaborating Centre for Determinants of Health.

The 8 steps for leading change | Kotter.

Determine how SDD will be collected for the identified programs/services.

Items to Consider:

- What specific SDD or data fields will help to answer the key questions?
- For what aspects of the program/service will SDD data be collected (e.g., will all clients be asked within a program/service, or only a subset or sample of clients)?
- The context within which the SDD will be collected and any options or accommodations that might be needed for collection (e.g., verbally, electronically, on paper; practitioner-led or client-led).
- What point in the service workflow makes best sense to collect SDD?
- Where/how will the data be captured (e.g., existing data system, secure webform; and, is the data stored securely?)

Resources

OHT-ÉSO Socio-demographic Data Common List

Other resources:
Data for Equity Guidelines | City of Toronto.

Data Collection Management and Planning Tools | Measuring Health Equity Project.

OHT-ÉSO Recommendations for SDD Collection and Storage

Other indicators sets referenced in Common List:

Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada | Canadian Institute for Health Information.

Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics | Ontario Health.

Recommended Socio-demographic Data Standards for Public Health Settings | Association of Public Health Epidemiologists of Ontario.

Summary List of Updated Socio-demographic Data Questions for Community Health Centres | Alliance For Healthier Communities.

Screening for Poverty and Related Social Determinants to Improve Knowledge of and Link to Resources (SPARK): Development and Cognitive Testing of a Tool for Primary Care | Upstream Lab SPARK Study.

Explore data governance frameworks and consider their application to ensure responsible, non-stigmatizing data collection and use.

Items to Consider:

- Establishing processes for early and ongoing engagement with First Nations, Inuit, Métis, Black, immigrant, 2SLGBTQ+, persons with disabilities and/or other communities that face barriers to ensure data governance principles are respectfully applied.

- The participation of community/population groups in SDD analysis and/or interpretation, particularly for dissemination of findings and/or recommendations emerging from the data.

- Exploring the need for data sharing agreements with community/population groups (as needed).

Resources

A Path Forward: Toward Respectful Governance of First Nations, Inuit and Métis Data Housed at CIHI | Canadian Institute for Health Information.

Health Data and Information Governance and Capability Framework | Canadian Institute for Health Information.

The First Nations Principles of OCAP | First Nations Information Governance Centre.

Indigenous Data Privacy Framework | Indigenous Primary Health Care Council.

Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities in Ontario | Black Health Equity Working Group.

CMAJ's New Guidance on the Reporting of Race and Ethnicity in Research Articles

Develop and implement a data completeness and quality monitoring plan.

Items to Consider:

- Establishing percent completion targets during a given timeframe.
- Regular sharing of completion rates with staff/teams who are collecting SDD to inform opportunities for process improvements, and to motivate ongoing collection efforts.
- Engaging staff to identify enablers and barriers to collection and explore opportunities to improve data completeness and quality (e.g., standing meetings or SDD community of practice).

Resources

Guide to Demographic Data Collection in Health Care Settings | Ontario Health, Sinai Health, UHN.

Data Quality Tools | Measuring Health Equity Project.

Data Audit Workflow Example | Alliance for Healthier Communities.

Develop and implement a data analysis and reporting plan.

Items to Consider:

- What is needed for analysis (e.g., data definitions, comparators (Census or other), frequency/timing for analyses, analysis notes for data fields).
- Existing guidance for stratified analyses (e.g., Canadian Institute for Health Information equity stratifier guidance).
- What proportion of the population are captured in the data? Is it representative of the population? Who is/isn't reflected in the data?
- Other types of analysis including disaggregation and intersectionality (e.g., gender- based, race-based, immigration, housing).
- A standard process for summarizing key findings/key messages and the use of inclusive language.
- Reviewing data reporting guidelines to address the needs of small populations.
- Engaging community partners to inform analysis, interpretation, and key findings (see step 4).
- Identifying affected or over-represented community groups and engaging prior to public sharing of findings and key messages to ensure messaging is not deficit-based nor contribute to mistrust (see step 4).

Resources

Guide to Demographic Data Collection in Health Care Settings | Ontario Health, Sinai Health, UHN.

Measuring Health Inequalities: A Toolkit. | Canadian Institute for Health Information.

Demographic Data Summary Analysis Tools | Measuring Health Equity Project.

Sample Workplan for Collecting Sociodemographic Data | Alliance for Healthier Communities.

Sociodemographic Data Collection and Use in Ontario CHCs – Report | Alliance for Healthier Communities.

Train staff and leaders on SDD collection.

Items to Consider:

- Building on the work to engage staff, develop training that emphasizes the purpose and utility of SDD. If staff and leaders understand the value of SDD, they will feel more comfortable and recognize their role in fostering an environment of trust on the part of the client to provide this information.

- Emphasizing the importance of informed consent for clients to provide SDD. If clients understand the rationale for collecting, they may be more likely to provide the information.

- Emphasizing the importance of humility and creating safety in collecting SDD. This may include guidance and/or training provided by representatives of local equity- deserving groups (e.g., locally-relevant history, how best to create safety in asking the SDD questions).

- Ensuring ongoing and adequate training for SDD collection and use, particularly for newly hired staff.

Resources

OHT-ÉSO SDD Collection Rationale & User Guide

Data Collection Tools | Measuring Health Equity Project.

Healthcare Provider Script for Administration of Socio-demographic Questions | Alliance for Healthier Communities.

Navigating Common Client Questions Regarding Data Collection | Alliance for Healthier Communities.

Staff Training Videos for Collecting Socio-demographic Data from Patients/Clients | Measuring Health Equity Project.

Staff Script for Collection of Racial/Ethnic Identity | Shared Health Manitoba.

Provide ongoing support to staff and clients to safely collect this information.

Items to Consider:

- Offering a variety of tools throughout the implementation process that are adapted to the specific context (e.g., visual aids (posters), laminated response sheets in multiple languages as appropriate, frequently asked questions with rationale for each data construct).
- Physical space(s) to ensure client and staff safety and privacy for SDD collection.
- Creating ongoing opportunities to gather feedback about asking SDD questions and collection, to support continuous quality improvement efforts.

Resources

Patient/Client Communication Tools | Measuring Health Equity Project.

FAQ Document - Gathering Information for Better Care: Sociodemographic Data | The Ottawa Hospital.

Client Brochure – Information on Sociodemographic Data Collection | Harrow Health Centre Family Health Team.

Appendix of Resources

Socio-demographic Data Indicators

OHT-ESO Socio-demographic Data Common List

Other socio-demographic indicator lists:

Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada | Canadian Institute for Health Information.

Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics | Ontario Health.

Recommended Socio-demographic Data Standards for Public Health Settings | Association of Public Health Epidemiologists of Ontario.

Summary List of Updated Socio-demographic Data Questions for Community Health Centres | Alliance For Healthier Communities.

Screening for Poverty and Related Social Determinants to Improve Knowledge of and Link to Resources (SPARK): Development and Cognitive Testing of a Tool for Primary Care | Upstream Lab SPARK Study.

Rationale for Socio-demographic Data Collection

OHT-ESO Socio-demographic Data Collection Rationale & User Guide

Other rationale for SDD collection:

Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres | Measuring Health Equity Project.

Lessons Learned from the Collection of Sociodemographic Data during the COVID-19 Pandemic | Public Health Ontario, based on research by Ottawa Public Health, Region of Peel and Upstream Lab.

- Final Report and Recommendations
- Resource Guide for Implementing & Scaling SDD Collection
- Webinar Recording

Socio-demographic Data Implementation Guide | Alliance for Healthier Communities

Resource Package to Support Socio-demographic Data Collection & Use | Alliance for Healthier Communities.

Project Planning Resources

Data Collection Readiness Checklist | Measuring Health Equity Project.

Guide to Demographic Data Collection in Health Care Settings | Ontario Health, Sinai Health, UHN.

SDD Collection Implementation Training Materials | Measuring Health Equity Project.

IAP2 Spectrum for Community Engagement | Tamarack Institute.

Community Engagement Planning Canvas Tool | Tamarack Institute.

Index of Engagement Techniques | Tamarack Institute.

Engaging Communities in your Data Collection Initiative| Health Commons Solutions Lab.

Let's Talk: Community engagement for health equity | National Collaborating Centre for Determinants of Health

The 8 steps for leading change | Kotter.

SDD Use Case Studies

Alliance Member Case Studies on Sociodemographic Data Collection and Use | Alliance for Healthier Communities.

Poverty: A Clinical Tool for Primary Care Providers | Centre for Effective Practice.

Gender-based Analysis Plus (GBA Plus) | Women and Gender Equality Canada

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Routine Collection of Sexual Orientation and Gender Identity Data: A Mixed-Methods Study | Upstream Lab SPARK Study.

Routine Identification of Patients with Disabilities in Primary Care: A Mixed-Methods Study | Upstream Lab SPARK Study.

Best Practices for Collection and Storing of Socio-Demographic Data

Data for Equity Guidelines | City of Toronto.

Data Collection Management and Planning Tools | Measuring Health Equity Project.

OHT-ÉSO Recommendations for SDD Collection and Storage

Guide to Demographic Data Collection in Health Care Settings | Ontario Health, Sinai Health, UHN.

Data Quality Tools | Measuring Health Equity Project.

Data Audit Workflow Example | Alliance for Healthier Communities.

Sociodemographic Data Collection and Use in Ontario CHCs – Report | Alliance for Healthier Communities.

Sample Workplan for Collecting Sociodemographic Data | Alliance for Healthier Communities.

Best Practices for Analyzing, Reporting, and Using Socio-Demographic Data

Guide to Demographic Data Collection in Health Care Settings | Ontario Health, Sinai Health, UHN.

Measuring Health Inequalities: A Toolkit. | Canadian Institute for Health Information.

Demographic Data Summary Analysis Tools | Measuring Health Equity Project.

Data Governance Resources

The First Nations Principles of OCAP | First Nations Information Governance Centre

Indigenous Data Privacy Framework | Indigenous Primary Health Care Council.

Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities in Ontario | Black Health Equity Working Group.

A Path Forward: Toward Respectful Governance of First Nations, Inuit and Métis Data Housed at CIHI | Canadian Institute for Health Information.

Health Data and Information Governance and Capability Framework | Canadian Institute for Health Information.

Staff Training Resources

Presentation: Using Data to Advance Health Equity | Alliance for Healthier Communities.

Introduction to Health Equity Online Course | National Collaborating Centre for Determinants of Health.

Training Video: Collecting Racial/Ethnic/Indigenous Identifiers during COVID-19 | Shared Health Manitoba.

List: Webinars on Racism, Anti-racism and Racial Equity | National Collaborating Centre for Determinants of Health.

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Client/Patient and Caregiver Communication Resources

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